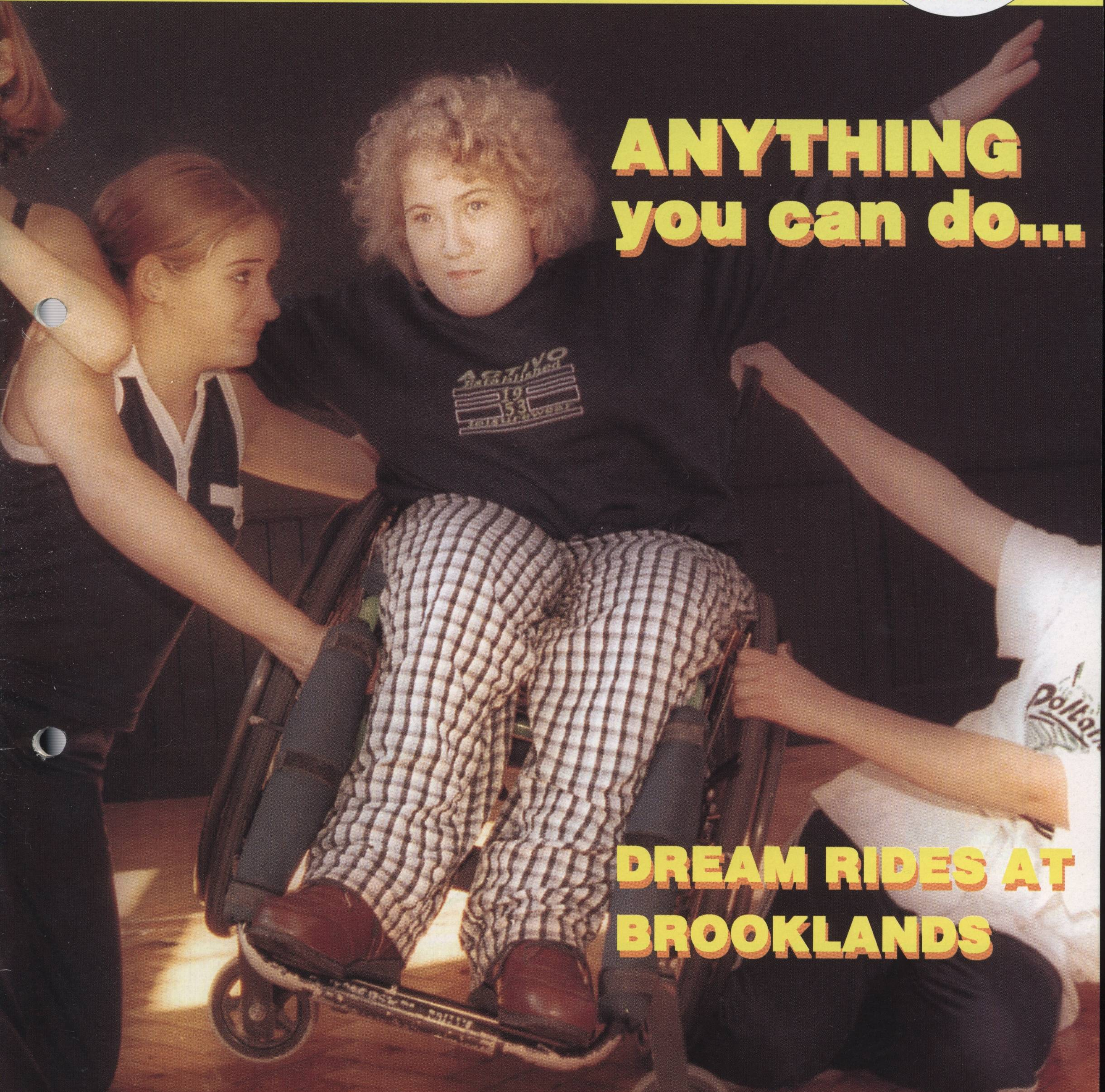
LINK

The magazine for people with Spina Bifida and / or Hydrocephalus



ANYTHING you can do...

DREAM RIDES AT BROOKLANDS

PRICE 80p

MAY / JUNE 2001 ISSUE 193

Meeting the demands of today's lifestyles

In today's changing world choosing a wheelchair for everyday use is not easy. RGK develop and manufacture wheelchairs and fully believe in flexibility, style, quality and the high performance of our product range.

With our extensive range of wheelchairs finding the right one for you won't be a problem.

All our wheelchairs are made-to-measure with a wide range of options to suit all your needs and all are available for a home demonstration trial period.

And with a commitment to every single customer it ensures that we work towards the goal of exceptional satisfaction for everyone who deals with us.

So if you are looking for flexibility in an ever changing world give us a call now on **01543 670077** and let the good times roll!

LET THE good TIMES ROLL!
RGK
WHEELCHAIRS

RGK Wheelchairs
Unit 8b/c, Chasepark Industrial Estate
Ring Road, Chasetown, Staffordshire WS7 8JQ

T: 01543 670077
F: 01543 670088
E: info@rgk-wheelchairs.co.uk
W: www.rgk-wheelchairs.co.uk

Customer satisfaction that exceeds expectations

LINK

Cover: Schoolgirl Erin Guthrie takes centre stage in a dance show choreographed by Candoco. Story, page 4

Editorial

Dear Readers

I WISH there was somewhere on mainstream TV where we could watch the disability news together.

There's nothing where we can be sure that, when we switch on, we will have an undiluted 20, 30 minutes or whatever of scheduling devoted to disability. Blow who shot Phil Mitchell, I want to gossip on the phone with Gerald Everness afterwards about Direct Payments, mobility components, even that chap with no legs who climbs mountains!

Telly's left a blank canvas for disability since they withdrew *From the Edge*, and ditched the *Link* programme.

Radio 4's *You and Yours* programme, with its irregular disability items, is no substitute. I mean, however worthy, who's listening just before lunchtime?

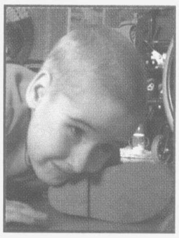
TV doesn't have to come up with a programme made to boost the ratings... because it won't! Just a little corner on the box, not too late at night, where thee and me, and Gerald, can catch up with what's going on.

Tony Britton

Tony Britton
Publicity Manager

contents

MPs visit ● Page 9



Morecambe ● Page 10

Hydrocephalus ● Page 12

Cheek swabs ● Page 13

Editor in Chief: Tony Britton **Editor:** Liz Cawthorne **Designer:** Tony Nero
LINK is published by **ASBAH**, National Centre, 42 Park Road, Peterborough PE1 2UQ

Subscriptions, Editoral, and Advertising inquiries to:

Liz Cawthorne, Link Editor
ASBAH National Centre, 42 Park Road
Peterborough PE1 2UQ
Tel: 01733-555988 Fax: 01733-555985
lizc@asbah.org

Audio-tapes available at no extra charge

Subscription Rates (six issues per year)

UK	**£4.80**
All European subs & Air Mail	**£15.00**
Outside Europe, surface mail only	**£7.50**

Patron: HRH The Duchess of Gloucester GCVO
President: Jeffrey Tate CBE

ASBAH exists to provide advice, support and advocacy to people with spina bifida and/or hydrocephalus, their families, and their carers.

ASBAH aims to empower its service-users by providing up-to-date information, extending their choices, and maximising their opportunities for independence.

postmaster@asbah.org
www.asbah.org

ISBN 1360-323X

Registered Charity Number 249338

New premium

A NEW disability premium can be claimed by people on Income Support, Job-Seekers Allowance, Housing Benefit or Council Tax Benefit.

The new premium is worth £11.05 for individuals, or £16.00 if both members of a couple satisfy the conditions.

It does not replace disability or severe disability premium.

You are entitled to the new premium if you or a member of your family (including children) receive the high rate of the care component of Disability Living Allowance, providing the claimant is below the age of 60.

The premium will not be paid to children or young people with capital over £3,000, or to hospital in-patients who are single and have been in hospital for more than six weeks.

For couples, it will not be paid if both partners have been in hospital for more than six weeks.

Toddler payout

SEVERELY disabled children as young as three can now claim higher rate mobility payments on the Disability Living Allowance.

Around 6,000 youngsters who cannot walk or have severely limited walking ability will benefit from the extra £38.65 a week. Previously, the minimum age of entitlement to this component was five.

The Government says the cash will enable some families to buy a car on favourable terms from Motability. The change is designed to reduce the disadvantage faced by many severely disabled children.

PHOTO: MARY NEALE

Anything you Cando...

DISABLED and non-disabled youngsters seized an opportunity to dance, giving vibrant and moving performances in an award-winning school-based project.

The two-year project, involving the Candoco Dance Company, won Poltair Community School and Sports College at St Austell, a coveted Youth Sports Trust Innovation Award.

Jackie Green, Poltair's head of dance, said: "Often children with severe disabilities, including wheelchair-users, do not think they can be dance performers.

"I wanted to bring together specialist dancers with skills in creating dance with both able-bodied children and children with physical and learning disabilities, to give them an equal opportunity to become dance performers and creators."

The project drew in pupils from colleges in Bodmin and Penrice, as well as St Austell, and from Doubletrees Special School at St Blazey.

Jackie enlisted the help of Kuldip Singh Barmi, choreographer of Candoco – the country's leading integrated dance company.

For one performance the children created their own sets and props, leading to a visually stunning performance which literally reduced the audience to tears.

"This was an incredible production in which it was impossible to tell which of the performers was able-bodied and who had physical disabilities," added Jackie.

● *Picture shows Erin Guthrie (centre) with other dance students from the Poltair and Doubletrees schools.*

Booklet packed full of information

INFORMATION on topics ranging from financial services to holidays is contained in a free booklet from Ricability, an independent research charity.

Who can help? is available by sending a large (A4) SAE and 33p in stamps to Ricability, 30 Angel Gate, City Road, London EC1V 2PT, tel: 020-7427 2460 minicom 020-7427 2469. Available on request in large print, on tape and in Braille. www.ricability,org.uk

Carol joins long wait for car conversions

NEW APPLICANTS who want to take on Motability cars which need substantial adaptations before they can drive them have been put on a waiting list... and it could take three and a half years to get to the head of the queue.

This exceptionally long waiting list has angered many disabled people who feel they are being let down by the organisation set up to increase their independence by getting them on the road.

Carol Hili *(pictured right)* was told she faced a three and a half year wait after she had applied for £10,000-worth of adaptations to a Citroen Berlingo Multispace vehicle so she could steer her electric wheelchair up a ramp and straight to the driving position.

"There's no way I can lift even a lightweight wheelchair into an ordinary non-converted car", said 27-year-old Carol, a full-time local government clerical assistant who has spina bifida and curvature of the spine.

"I have been on the waiting list since last August. I shouldn't have to rely on my parents and family to take me to and from work every day, out shopping and to hospital appointments. It took me two years to pass the driving test and so far all that hard work has been for nothing. It's an appalling state of affairs."

Carol, who lives in Dagenham, Essex, has complained to her MP Judith Church, who in turn told Social Security Secretary Alastair Darling by letter that the long wait was disgraceful.

The MP wrote: "Miss Hili has been through every hoop imaginable to train, to get employment and to sustain it for more than 10 years. She has also passed her driving test which required perseverance that I utterly admire. She is a person of great courage and exceptional modesty who has just got on with her life, despite considerable disability."

Motability leases thousands of cars every year to disabled people, who sign over their higher rate mobility benefits to fund the rentals. But customers needing additional expensive adaptations before they get on the road must first apply to the government-backed Mobility Equipment Fund to meet the extra costs.

A Motability spokesman blamed increased demands from existing customers whose condition had deteriorated for his organisation's inability to take on new customers wanting help from the Mobility Equipment Fund. "The waiting list will remain closed until significant inroads have been made into the current list, which will not be until later in the year."

ASBAH contacts

● NATIONAL CENTRE
42 Park Road
Peterborough PE1 2UQ
Tel: 01733-555988
Fax: 01733-555985
postmaster@asbah.org

● ASBAH EAST
42 Park Road
Peterborough PE1 2UQ
Tel: 01733-555988
Fax: 01733-555985
marym@asbah.org

● ASBAH NORTH
64 Bagley Lane, Farsley
Leeds LS28 5LY
Tel: 0113-255 6767
Fax: 0113-236 3747
nro@asbah.org

● ASBAH N. IRELAND
Graham House
Knockbracken Healthcare
Park, Saintfield Road,
Belfast BT8 8BH
Tel: 028-9079 8878
Fax: 028-9079 7071
margarets@asbah.org

● ASBAH SOUTH EAST
209 Crescent Road
New Barnet, Herts EN4 8SB
Tel: 0208-449 0475
Fax: 0208-440 6168
sero@asbah.org

● ASBAH IN WALES
4 Llys y Fedwen, Parc
Menai, Bangor, Gwynedd
LL57 4BL
Tel: 01248-671 345
Fax: 01248-679 141
elini@asbah.org

Avoid trouble on long-haul flights

TRAVELLERS taking long-haul flights can do much to help themselves avoid so-called 'economy class syndrome' which has received so much media attention recently.

Any journey where you are immobile for long periods can increase the risk of deep vein thrombosis (DVT) although the risk of this occurring while travelling by air is extremely low.

DVT occurs when a blood clot forms, usually in the lower leg. This is a serious medical condition and needs treatment with blood thinning drugs (anticoagulants) to prevent clots breaking off from the DVT and travelling to the lungs causing significant illness and, on rare occasions, death.

People at increased risk include those with a history of thrombosis, pregnant women or those taking an oral contraceptive pill, those recently hospitalised, smokers, obese people, some patients with congestive heart failure and people with malignant disease. Dehydration may make the problem worse.

According to ASBAH's medical advisers, the steps to take to avoid DVT are the same for wheelchair-users as they are for everyone else – keep moving and drink plenty (but avoid alcohol).

Keep moving by regularly shifting your seated position and by raising and gently massaging your legs. Perhaps your travelling companion will help you. Avoid crossing your legs or sitting with one leg bent across the other knee for long.

Tightly fitting socks and shoes are best avoided but light support stockings or tights are helpful. Feet swell on flights anyway so you could loosen laces or undo shoe straps before setting off.

Giving up or reducing the amount you smoke is another sound way of reducing your chances of DVT.

For some people, taking Aspirin may be helpful as it thins the blood and is believed by some doctors to help prevent clotting. To do any good, you must start taking it a week before flying but ALWAYS consult your GP or neurosurgeon before taking Aspirin as it is not suitable for everyone.

On the flight, seek medical attention if you notice that your legs are more swollen than usual and/or they are red, painful. There may also be heat in the leg area. You may also feel generally unwell.

Urgent medical attention is required if you experience shortness of breath or pain in the chest.

Meeting for people with BIH

PEOPLE living with Benign Intracranial Hypertension, one of the least understood conditions involving fluid build-up in the brain, will get a rare chance to talk to one another in Surrey on Saturday 2 June.

ASBAH regional co-ordinator Jo Francis is arranging a free informal get-together at the civic centre in Banstead between 11am and 2pm. She will be joined by area adviser Diane Morgan; Lynne Minister, one of the founders of our BIH support group, also hopes to get along.

Jo said: "We know a number of people in our region, who feel very isolated with their BIH. Typically people with it spend a lot of time in hospital, they get awful headaches which go on and on and it can be a very depressing kind of illness."

The meeting will be very informal. Light lunch will be offered. If you would like to attend, please phone Jo or her secretary Denise on 0208-449 0475, email: jof@asbah.org

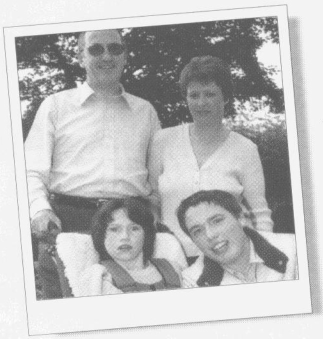
BIH is so rare that it affects only one or two in every 100,000 people, most of them women. It may be associated with overweight, but losing weight does not appear to arrest the condition – although American research indicates that a six per cent weight loss leads to disappearance of the associated papilloedema (swelling of the optical discs).

● *ASBAH has an Information Sheet about BIH. For a copy, send a large SAE to Information, ASBAH National Centre, 42 Park Road Peterborough PE1 2UQ.*

a whole range of possibilities for wheelchair passengers

For over 30 years Gowrings Mobility has supplied **Chairman** wheelchair accessible cars and people carriers across the UK. Today, as Europe's leading manufacturer of wheelchair accessible vehicles, Gowrings has over 4000 satisfied customers on the road. The Gowrings range offers a whole world of possibilities for wheelchair users and carers alike including:

- **Nationwide** free test drive and demonstration service
- 3 year **no quibble** conversion **warranty**
- Friendly and **experienced** sales advisors
- All servicing carried out at your **local** garage
- All **right hand drive** vehicles for ease of use



> **"We chose the Chairman Zafira because it's a good looking, modern car which will meet all the special needs of our family."**
>
> **MRS WARNE – BERKSHIRE**

Chairman Dispatch

The Chairman Dispatch, which can seat up to six passengers including two wheelchair users, provides all the comfort and luxury of a modern MPV with the performance of a family saloon.

Chairman Voyager

As the world's top selling people carrier, the Chairman Voyager, offers first class levels of equipment and carries five passengers and one wheelchair user.

Chairman Multispace

The Chairman Multispace, in petrol or diesel versions, offers a spacious interior and has room for four passengers and one wheelchair user.

Chairman Kangoo

The Chairman Kangoo is one of our most popular vehicles with room for up to four passengers including a wheelchair user. Its distinctive and compact design provides a spacious and practical mobility solution at an excellent price.

Chairman Vito

Offering one of the most comprehensive ranges of options, the Chairman Vito accommodates up to three wheelchair users and four other passengers.

Chairman Zafira

The stylish Chairman Zafira offers superb handling, comfort and performance with plenty of space – room for up to five passengers and a wheelchair user.

To find out more or for friendly advice as to which would suit you, call the **Freephone** number below for your free **Chairman** information pack, or call our **Sales Advice line** on **01635 529500** or call our website.

All prices correct at time of going to press

Used Cars from £5,200

gowrings mobility

a whole world of possibilities

Motability* **accredited supplier**

Call Free 0800 220878

www.gowringsmobility.co.uk

*This is a trade mark of Motability registered charity number 299745

Gowrings Mobility Ltd. Bone Lane, Newbury, Berkshire RG14 5UE. Tel: 01635 529500. Fax: 01635 529400.

Trust helps us spread the word on hydrocephalus

A HYDROCEPHALUS Information Campaign targetted primarily at school staff will soon by launched by ASBAH – with funding obtained from a specialist trust set up within MENCAP.

The purpose is to raise the profile of the condition in mainstream schools which have pupils who have hydrocephalus. The money will pay for hydrocephalus study days round the country, special visits to schools to tell staff about behavioural problems particular to children with the condition and to pay for the wider distribution of ASBAH's acclaimed education topic sheets on the subject.

The study days will also be set up to appeal to parents and carers with concerns about their children's education. Our 1999 book, 'Hydrocephalus and You' – costing £7.50 inc p&p – may also be able to be circulated much cheaper.

Milly Rollinson, ASBAH's assistant director (services) said: "Many children with hydrocephalus in school simply do not get the level of support required to achieve full potential because their disability is invisible. Staff need to be aware of their problems, so no child need fall through the net of available support.

"Quite often, this requires close partnership and monitoring between school and home. Parents should be sharing the responsibilty for these arrangements with the teachers."

Voluntary sector launches its continence manifesto

THE voluntary sector's *Manifesto for Continence* will be launched later this year at an *In*Contact conference in Derby – where hundreds of people with incontinence problems can listen to experts, and swap ideas and experiences.

The conference will be held on 4 and 5 September. There will be free places for ASBAH members. ASBAH will be participating in a range of workshops, talks and displays.

Some financial help with travel and accommodation will be available for people on low income. And there's still time to feed your views of your local continence services to *In*Contact for inclusion in the Manifesto. Ask to be sent a reply-paid postcard for your views *(contact details below).*

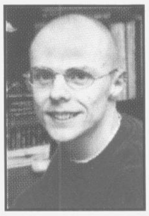
*In*Contact director Joylon Rose predicted huge interest in the event. "It'll be the first time that so many consumers will be meeting under one roof," he commented.

● *For a postcard and/or a registration form, phone 0207-700 7035, info@incontact.org*

Harry's gone!

SIR HARRY SECOMBE, ASBAH's first celebrity sponsor, lost his fight against cancer in April. The loveable ex-Goon campaigned for us in our early days. He was aged 78.

Told he'll get better!



A YOUNG man with spina bifida occulta was refused DLA mobility benefit because Benefits Agency staff mistakenly thought he would get better. He needed the mobility component so he could start paying for an electric scooter.

Daniel Linger from Spalding, Lincs failed to persuade an appeal tribunal in 1998 that he needed DLA mobility so he could sign the finance agreement on his £4,000 scooter.

After discussing tactics with a friendly local solicitor, he then reapplied for mobility , threatening to chuck the book at the Benefits Agency for maladministration and call in his local MP.

It worked. After a three-year wait, he was able to go out and buy his scooter.

"It was ridiculous. All they saw was a young man who they said would get better and didn't need the mobility component," said Daniel, now 34. "They had no idea at all about how my physical condition had deteriorated. It was a real case of 'don't know, don't care'."

‘Don’t know, don’t care’ agency staff stand accused

WIDESPREAD complaints about how Benefits Agency staff handle many benefits claims have been put in person to a government minister by ASBAH.

Government minister Hugh Bayley MP (left) and Helen Brinton MP greeted by ASBAH executive director Andrew Russell.

Department of Social Security minister Hugh Bayley MP was told that many staff at the Benefits Agency had a ‘don’t know, don’t care’ attitude when considering thousands of claims for Disability Living Allowance.

About one in three of all claimants were failing to obtain DLA at the correct level, if at all – because poorly-trained Benefits Agency staff missed vital clues when assessing the claims, or failed to spot when people with learning and perceptual problems were overstating their own levels of ability.

Complaints were also levelled at examining doctors employed by the Benefits Agency. ASBAH told the minister that their reports were often difficult to read, contradictory and failed to record information properly.

The meeting – hosted by ASBAH executive director Andrew Russell – took place at our national centre in Peterborough at the end of February. It was arranged by local MP Helen Brinton.

The minister was told that the high success rate in taking rejected DLA claims to review and appeal suggested Benefits Agency staff had huge gaps in knowledge about the effects of disability on people’s lives.

These gaps needed to be plugged by proper training, in which ASBAH and other voluntary organisations were willing to get involved. Good training could help the Benefits Agency to save money now spent defending bad decisions, and so put it more quickly into the pockets of deserving claimants.

Mr Russell and key staff were joined at the meeting by Graham Nickson, policy and campaigns manager for Headway, the association for brain-injured people. Together, we help hundreds of children and adults every year obtain the correct level of DLA – the benefit at the heart of state support to people with disabilities.

A recent survey by the Down’s Syndrome Association revealed that one in three of their DLA claimants failed to receive the benefit at the correct level, if at all. But four out of five of rejected claimants eventually got the correct amount at review or appeal.

After the meeting, Mr Russell said the minister had pointed to various measures within the Benefits Agency aimed at improving decision-making on DLA claims. These included a six-week, full-time training course for decision makers, and a written exam for examining doctors.

He added that voluntary organisations including ASBAH wanted to get involved in training to add value, particularly in respect of claims from people with less visible neurological impairments like hydrocephalus.

Confusing doctor’s report

STELLA is 22 years old and has spina bifida and hydrocephalus. Stella’s benefit came up for review and her care component was reduced from middle rate to lower rate.

A doctor’s report was requested by the decision-maker on behalf of the Secretary of State. The doctor’s report is vague and fails to state the facts accurately. In one part of the report the doctor reports that Stella has right hemiparesis and uses both calipers and a wheelchair. In another part of the report he then states that Stella has full function of her lower limbs.

Stella asked for a reconsideration but the decision was upheld by a second doctor. The case went to tribunal for a final decision.

family weekend

Headway Hotel, East Promenade,
Morecambe: 3 – 4 March 2001

Our yearly gathering moves to Morecambe

BBC
CHILDREN
IN NEED

Words:
Rosemary Batchelor
Senior Adviser, Health & Policy Issues, ASBAH

THIS year we moved to the North of England to hold our Family Week end at a new venue in Morecambe, Lancashire.

Our eighth annual weekend attracted more applicants than ever before in its aims of bringing families together and fulfilling the very different needs of parents, disabled children (aged six and under) and their brothers and sisters.

There were 35 children – the oldest 12 and a mum of 16 – and 32 adults.

Seventeen of the children, aged from 11 months to six years, had spina bifida and/or hydrocephalus. Of these, one girl was blind and a boy had a hearing impairment; others had associated epilepsy or behavioural problems; one had apnoeic attacks.

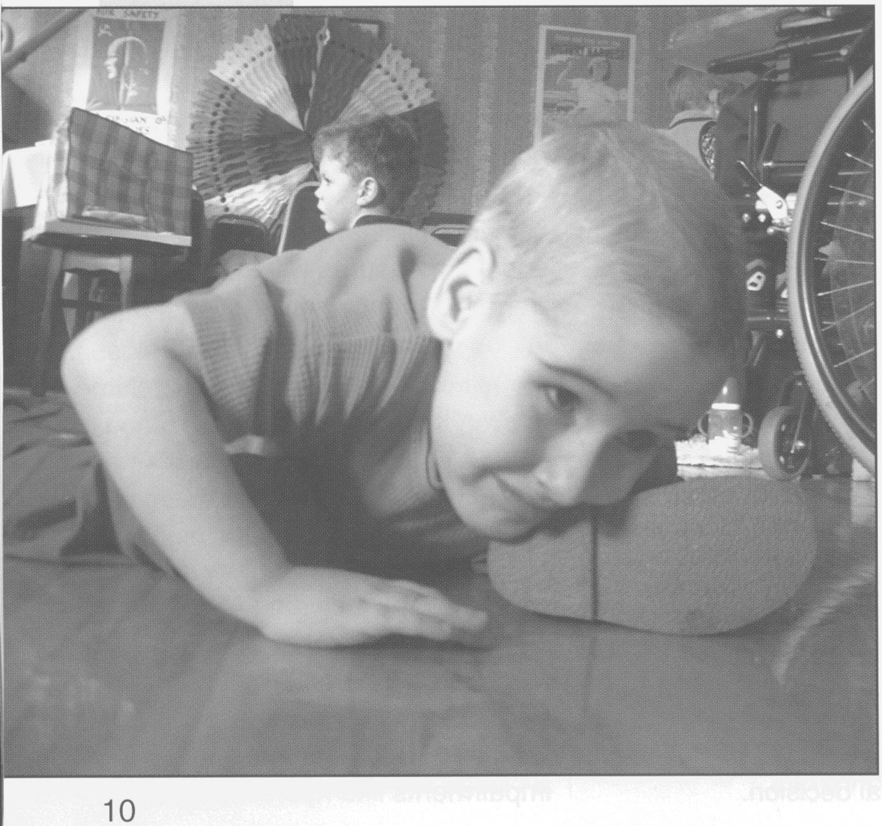
Most were accompanied by parents though two children had grandparents with them. For another child, an aunt and cousins accompanied mum as auntie is his day-time carer.

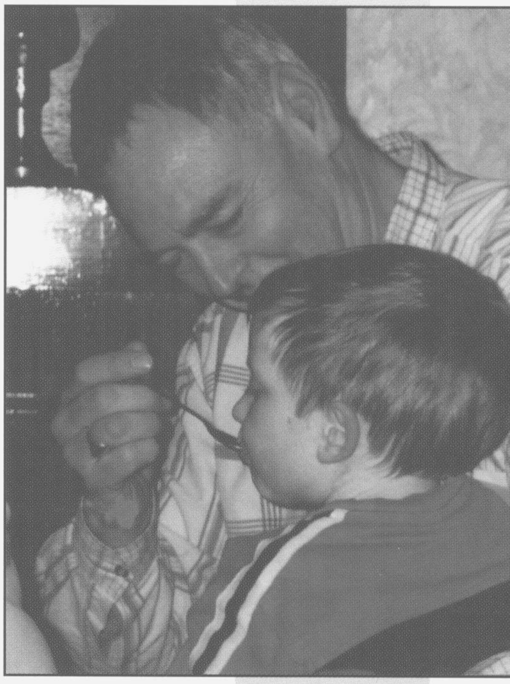
A total of 18 ASBAH staff and our chairman, Peter Cottingham, attended. A student nurse and a PhD student were volunteers. Staff included advisers with expertise in education, occupational therapy, mobility, continence, benefits, feeding problems and behavioural problems: one was a psychologist, two were nursery nurses and several had nursing backgrounds.

While the children worked in groups, the adults had lectures and time to share experiences and ideas.

On the Friday night, while the parents had a quiz, the children were ready for party games – musical statues and team games; a mini disco and story-telling.

Next morning, the sun was shining and the 5–7s went for a walk along the beach opposite the hotel.





This gave some privacy for the over-eights to do some group work exploring their feelings about their disabled siblings and time to talk about the effects this had on their lives.

While the 2–4s did a giant painting on the ballroom floor, the older children went to Laser Megazone in Morecambe. This was much enjoyed by the over eights, less popular with the 5–7s and much less of a success with the staff who took them!

That evening, ASBAH staff ate high tea with the children while their parents got ready for their candle lit dinner. After the chaos of eating with 35 children, we hoped an entertainer would keep the children happy. Not so! So ASBAH staff took over and improvisation was the name of the game.

On Sunday, the over-fives went to Lakeland Oasis Wildlife Park, which was luckily unaffected by the foot and mouth outbreak.

The weather was bright, sunny and cold as they excitedly packed into the minibus with eight members of staff, promising to be back for lunch.

The babies slept in the creche; the 2–4s, still tired from the previous evening, sat happily to watch *Bob the Builder* to cuddle up for stories or to draw.

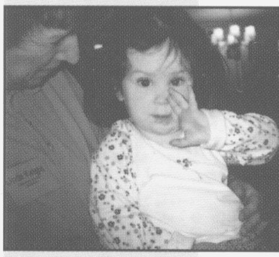
All too soon – for the families – it was lunch-time and the end of the weekend. Over lunch they took every opportunity to ask questions, request information or just to chat.

We packed the toys and returned them to the Toy Library then started the long journey south and home!

And what did we learn?

- That children with profound disabilities can be part of a group with help and a little thought.
- That learning is a two-way process and a four-year-old can teach us enough British Sign Language in a weekend to make us effective communicators.
- That our wheelchair user member of staff has a talent for giving children rides!
- That, although exhausted, we know that we gave the children a super weekend.
- The parents also enjoyed it and were more than grateful for the information and support unavailable elsewhere.
- That parents and children want "more of the same."

The evaluation sheets reflect the enthusiasm of parents and children for these courses. We are grateful to the Morecambe Toy Library for all their help and to financial support from the BBC Children In Need Appeal.



50 years of not knowing

I WAS gob-smacked to read in the March *Link* about Barry Duffin. The similarity between our experiences is astonishing.

My name is Leila Thomas and I have hydrocephalus. You may think this is not a good club to belong to, but I am very pleased!

I have struggled all my life with migraines/vomiting/ balance/memory problems, periods of sudden blindness etc. Having an undiagnosed disability means forever trying to work (I proved to be too accident prone) and forever trying to claim benefits (I could write a book about my failures in that department) and several times nearly losing the roof over our heads (I have a son). It has made life very stressful.

Now at 50 years of age, an MRI scan has revealed I was born with hydrocephalus. I have avoided all the many problems associated with shunts, but I would not wish my life on anyone.

As I had a violent childhood, after my mother died when I was very young, my problems were either classed as psychiatric or simply dismissed/ disbelieved. After all, I sat there looking perfectly fine.

By the age of 15, I was living in a cardboard box under Charing Cross Bridge in London (how low can you get!). I certainly didn't deserve even an appointment with a neurologist let alone an MRI scan. I wouldn't have got one either, if I hadn't paid £130 to see a private one.

Now my life has been transformed. I am awaiting a third ventriculostomy, the surgeon informed me my ventricles are huge. I have no idea when but I have ASBAH, my knight in shining armour called Margaret Stanton. She has visited me and not rushed me out after 10 minutes, giving me time to explain my many symptoms/ problems/fears etc. She has brought order to my chaos and addressed each problem with practical help.

All this has happened because I am in 'the club'. Trust me, it's better than being out.

By Leila Thomas, Ebbw Vale, Gwent

Research extended

A RESEARCHER, looking at what it is like to live with acquired hydrocephalus or benign intracranial hypertension (BIH), now wants to hear from anybody in the UK.

Previously, Leslie Gelling, based Addenbrooke's Hospital, Cambridge was restricting his study to people who lived or worked in the Cambridgeshire area.

Now he plans to include all those who might be interested. They will be invited to write a detailed 'story' in which they describe their experiences once they have received further information and some guiding questions.

Since our last report on this study in *Link*, many people have expressed an interest by phone or email and nine interviews had been completed as this issue went to press.

Leslie said: "These interviews have provided some excellent information about peoples' experiences but the study still has a long way to go and it is too soon to draw any conclusions."

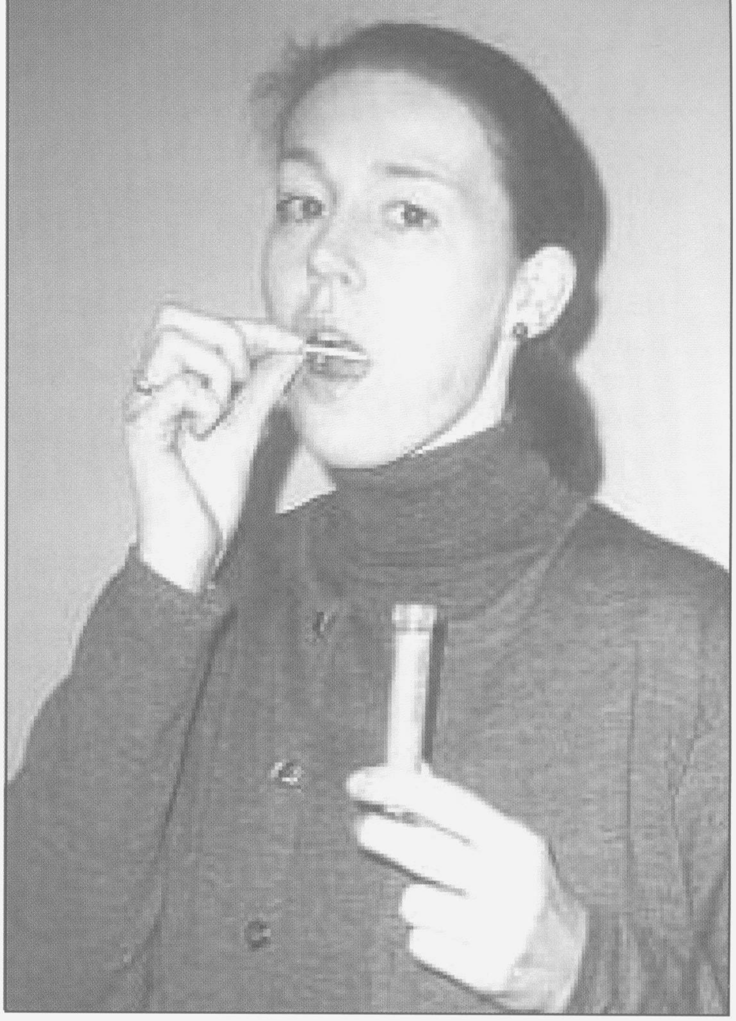
It is an important aspect of this study that the research is being undertaken in collaboration with participants.

Leslie explained: "Everyone who becomes involved will continue to be involved at all stages as long as they wish to do so. Participants will be asked to comment on the findings, as they emerge, and suggest how reports or publications might be improved prior to publication."

● *If you would like to become involved, phone Leslie Gelling on 01223-216146 or email: lhg23@medschl.cam.ac.uk*

4-page Link supplement

DO THIS – you may help solve the riddle of spina bifida



● *Dublin project manager Mary-Patricia McKeever shows how easy it is to self-administer a cheek swab.*

ASBAH service-users in England and Wales are to be invited to take part in a study to find the genes which make some people more prone to spina bifida than others.

A simple test will involve collecting your own DNA samples, by swabbing the insides of your cheeks and upper lip with cotton buds for at least 10 seconds. This will help scientists build up a picture of the genes which are implicated in spina bifida, and other neural tube defects.

The scientists hope that whole family groups will take part.

But, even if that is not possible, cheek samples from either parent will still be welcome – as will samples by themselves from people with spina bifida or other NTDs.

The researchers will send out the cheek swab kits. But only after receiving your consent. ASBAH will mail current service users direct, inviting them to take part, together with an information leaflet and a prepaid card for their replies.

If you volunteer, you will go into a study being conducted by a team based in the Republic of Ireland.

But readers in the North of England – where other scientists are looking at the subject from a slightly different viewpoint – may also be asked if they would like to take part in a more detailed study.

This will involve a visit from a nurse, who will take a blood sample and interview the family. This, in turn, may lead to an invitation to take part in a more detailed family-based study.

The individual results are confidential. No individual results from the DNA analysis or the questionnaire will be released. The scientists will, however, gladly send a summary of the results to people involved, once the research is finished.

The informed consent of all participants will be required.

Taking part is entirely voluntary. No pressure will be put on anyone to join the study. Anyone can withdraw at any stage. If you don't want to take part at all, simply ignore our mailing.

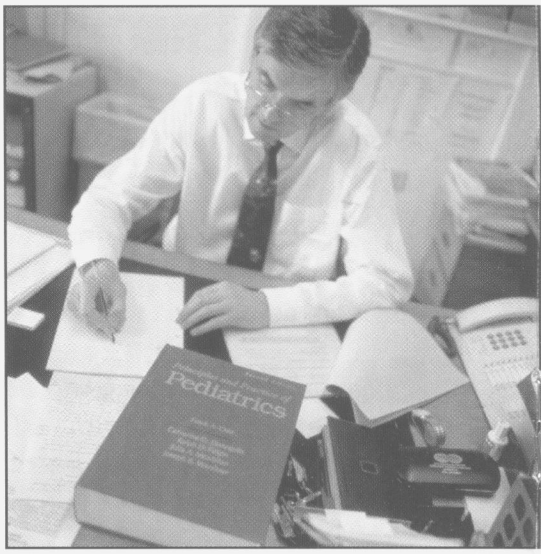
ASBAH and the researchers recognise that some disabled people feel strongly against genetic research, and will not take part.

We shan't be mailing readers in Northern Ireland, where DNA samples have already been supplied by many members.

$3m study

RESEARCHERS from Newcastle University, University College London, the Health Research Board in Dublin and Trinity College, Dublin, have been researching spina bifida and other NTDs for over 20 years.

In more recent years, they have greatly expanded their work. They now work with the National Institute of Child Health and Human Development, a division of the National Institutes of Health of the United States Government, on a $3 million contract for a collaborative three-year study into the genetic causes of NTDs.



● *Dr Peadar Kirke (right), principal investigator with the Health Research Board, Dublin.*

Link supplement, page ii

NEURAL tube defects happen when the neural tube, which becomes the baby's spine and brain, does not form properly during the very early stages of pregnancy.

Spina bifida is the most common of these conditions, followed by anencephaly when there is absence of brain and skull tissue. Babies with anencephaly do not survive. Rarer NTDs include encephalocele and iniencephaly.

Despite a reduction in NTD pregnancies in recent years, they currently affect about one in every 1,000 pregnancies in the UK.

Scientists are not sure what causes these conditions but a major transatlantic research study is under way into how NTDs might be inherited from our parents, and how our genes interact with what we eat and the environment in which we live.

Researchers in England, Ireland and the United States have already shown that pregnancies in which the baby has an NTD are characterised by low maternal blood levels of folate and vitamin B12 in early pregnancy.

The research has revealed that this is unlikely to be due solely to low intake of folate and B12, but is probably connected to an inability in either the baby or the mother to metabolise these essential nutrients.

Using gene analysis, the group discovered a defect in an enzyme associated with the metabolism of folic acid. Although this enzyme defect is quite common in the general population, in Ireland it is twice as common in people with spina bifida. This was the first genetic risk factor ever found for spina bifida, and it is important to find out if it is also a risk factor for England and Wales.

Another aim is to find other genes that may be involved, and to examine the possible relationship between genes and spina bifida.

Depending on what enzymes are involved, it may be possible to offer further protection to women planning a pregnancy by, for example, giving vitamin B12 in addition to folic acid.

This new work may help to discover why a quarter of all women and babies do not respond to folic acid. It may also lead to the creation of new public health strategies to help prevent women having more affected pregnancies.

The Newcastle University research team is studying the subject from a different perspective. Scientists there are looking at the genes involved in folate absorption and folate metabolism.

Their work has begun in Cumbria and will eventually take in the whole of the Northern Region. They are also interested in other birth impairments as there is some evidence that the causes of NTDs are common to other impairments, such as heart malformations.

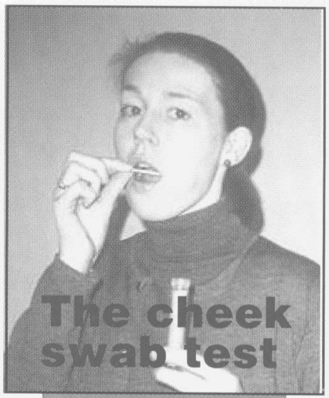
Proud record of achievement

● *(left) Senior researchers in Dublin with members of N Ireland ASBAH.*

INTERESTED? WELL, PLEASE DON'T DO ANYTHING YET

Link supplement, page iii

Three simple steps to give your DNA



THE WAY we are – the colour of our eyes, our height, the size of our feet, the shape of the nose, for example – is determined by a set of instructions contained in our DNA.

Genes are distinct sections of DNA, which we inherit from our parents. It is thought that humans have about 30,000 of them. Faulty genes can lead to the development of certain conditions or illnesses.

If you agree to supply cheek swabs, these will provide enough DNA to study your genes.

The researchers want, if at all possible, to make contact with the person with an NTD, and both parents – but samples from one parent only will be fine. Samples will also be welcome on their own from people with NTDs, if neither parent is available.

WHAT YOU HAVE TO DO

STEP 1: Find out all about the study, and ask any questions.

As well as reading information sent to you, you need to read and sign a consent form.

STEP 2: If you take part, you will be asked to fill in a questionnaire. This will take about 20 minutes. You will be asked about vitamin intake, medical and family history. If you are a mother who has had a child with an NTD, you will also be asked about your pregnancy.

STEP 3: The researchers will send you a pack of cheek swabs. Use the cotton buds they supply to collect cell samples from the inside the mouth. This is done by firmly brushing the cotton end of the swab against the inside of the cheek, rubbing each swab for at least 10 seconds. Different areas of the mouth should be used for each swab.

The different areas include the inside of the cheeks and the inside of the upper lip. Avoid the teeth, tongue and back of the mouth. After swabbing, place the buds in the tubes provided and seal them tightly. Put the tubes in the plastic bag provided, returning it to the laboratory by free courier service using the pre-addressed jiffy bag provided.

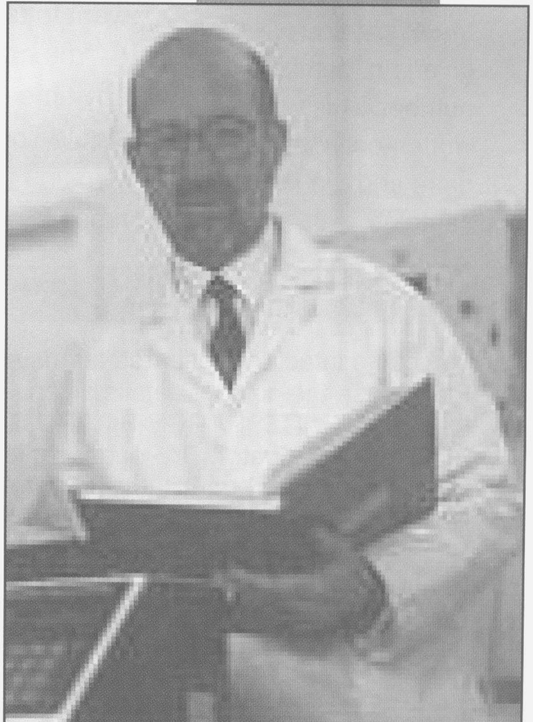
NORTH OF ENGLAND

Families in the North of England, who consent to take part, may also be contacted by the Newcastle research team who are conducting a more detailed phase of the study.

This would involve being visited by a nurse, who would like to collect a blood sample and carry out an interview. Blood contains more DNA than a cheek swab, and allows folic acid and vitamin B12 analysis to be carried out.

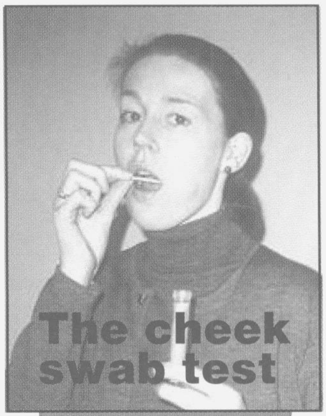
Families taking part, who have more than one relative with an NTD, may be invited at a later date to take part in a more detailed, family-based study.

● *(below) Professor John Scott, from Dublin, one of the leaders of the study.*



ASBAH WILL SEND YOU THE PAPERWORK FIRST

Private and respectful



The cheek swab test

PEOPLE who take part in this study will have the satisfaction of knowing that they have helped researchers to identify the genes that may be implicated in neural tube defects.

This will help researchers understand what causes spina bifida and other NTDs and how they might be prevented.

The results will only be used for research. Personal results from your DNA analysis or from the questionnaires cannot be passed over to you.

However, the team will gladly send a summary of the results to each family when the research project is over.

CONFIDENTIALITY

When you take part in the study, you will be given an identification number. This wll be written on your questionnaire and the DNA samples.

This means that any information you give to us will be held in strictest confidence. Only members of the research team will be allowed to see it.

Information sent to the United States will only have identification numbers and no names.

The study has been approved by the necessary ethics committees.

WHAT ARE MY RIGHTS?

You choose if you want to take part.

You can withdraw at any time during the study. The choice remains yours at all times.

We respect the fact that some disabled people are not in favour of genetic research, and will not want to take part.

● *(below) Deborah Watson, research administrator, will take many of your calls.*

FINDING OUT MORE

You can contact the research teams at any time. Please use the contact details given.

HEALTH RESEARCH BOARD, DUBLIN
Principal investigator: Dr Peadar Kirke
Project manager: Mary-Patricia McKeever PhD
Research co-ordinator: Miriam Lynch MPsychSc
Research officers: Helen Burke BSc,
Sharon Murray RGN RM
Research administrator: Deborah Watson BSc
Freephone: 0-800-1699050
email: childhealth@hrb.ie
Child Health Division
The Health Research Board
73 Lower Baggot Street
Dublin 2, Ireland

UNIVERSITY OF NEWCASTLE UPON TYNE
Principal investigator: Prof John Burn
Project manager: Caroline Relton PhD
Research nurse: Pat Jonas RGN RM
Tel: 01946-693181, ext 4250 (Pat Jonas)
email: caroline.relton@westlakes.ac.uk
The Genetics Unit
Westlakes Research Institute
Moor Row
Whitehaven CA24 3JY

TRINITY COLLEGE, DUBLIN
Principal investigator: Prof John Scott
Senior scientist: Anne Molloy, PhD

National Institutes of Child Health and Human Development, USA
Principal investigator, Dr James Mills Senior geneticist, Larry Brody PhD

obituaries

Sqn Ldr Ivor Davies RAF (Retd)

IVOR Davies made his weight felt at several ASBAH pre-formation meetings, and joined the first executive committee in 1966. He died in February, aged 78.

Before the ASBAH founding, he had already created out of nothing what was known as the North Hants group, following the birth of his son Andrew. Ivor was a flight lieutenant in the RAF on flying duties from Farnborough.

Frank Armour, one of ASBAH's first employees, recalls: "Ivor was the nearest thing to a human dynamo that most of us ever met. It was his tireless determination which ensured that ASBAH became active and dynamic at a time when legal and financial difficulties seemed interminable. 'Giving up is not an option' was his watchword and in his forthright manner he ensured the rest of us kept at it!"

Ivor Davies joined the RAF in 1941, serving in Bomber Command during the war. He was awarded the Air Force Cross, continuing to fly until three years before retiring in 1977 as a squadron leader.

During the following 10 years he was a quality assurance manager in the aerospace industry.

For the last seven years of his life, he was hon welfare and benefit officer for Age Concern at Aylesbury, Buckinghamshire – still working for Age Concern until the day before he died.

Ivor recently celebrated 55 years of marriage. He is survived by his wife Joyce, a son, two daughters and four grandchildren. The funeral was held at RAF Strike Command HQ in February.

Colin Runagall

A FOUNDER member of Leicestershire ASBAH, Colin Runagall, died suddenly in March.

Mr Runagall, a draughtsman, set up the group in 1963 after the birth of his twin daughter, Julie, who has spina bifida and hydrocephalus.

He served on the committee, became chairman and then later served as a trustee. He and his wife Eileen also maintained the association's chalet in Norfolk.

Alison Twomlow, LASBAH secretary, said: "Colin was a mine of useful information and was the one who always thought things through thoroughly, and could be relied upon to pull an, at times, unruly committee back into order".

Colin, who lived in Birstall, leaves a wife, a son, two daughters, partners and grandchildren.

MBE for leading light in Welsh voluntary sector

A WOMAN who has helped countless people with diabetes since she herself was diagnosed nearly 21 years ago, has been awarded an MBE.

Wendy Gane, who also has spina bifida, was presented with the honour by The Prince of Wales at Buckingham Palace.

The 42-year-old, who has to inject herself with insulin four times a day, was rewarded for her work with Diabetes UK which started when she formed a support group in her home town of Cwmbach. This developed into her taking a lead role on a video, leaflets and conferences and seminars which have brought together patients and professionals.

Now SE Wales co-ordinator for Diabetes UK, Wendy met Wales Assembly Health Minister, Jane Hutt, four times last year. In 1998 she won the H G Wells Award from Diabetes UK for improving services for diabetes patients in Wales, followed by the Good Health Wales Award from Health Promotion Wales. A patient survey which she has recently helped set up has been commended by the Audit Commission.

Wendy said: "It is the young people with diabetes who inspire me. They are the future and I want to work so that services improve for them."

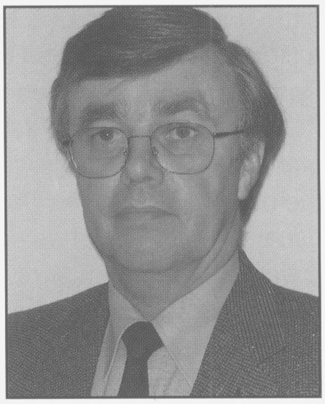
Wendy was joined by husband Michael *(left)* and brother Jonathan. "I was delighted that my family were there with me and was impressed at how much Prince Charles knew about me."

Best of luck, Wendy!

ASBAH receptionist Wendy Titman, whose voice is known to thousands of people who have called national centre, has retired early. She is moving to Spain with husband Gordon – his health improves in warmer weather. After selling their house, they fly to Tenerife for a few months before moving to mainland Spain. Wendy said: "I will miss ASBAH. I got to know a great bunch of people."

Vic Boston in the chair

LET'S hope there are no nasty tumbles ahead for Vic Boston, the new chairman of ASBAH's Medical Advisory Committee, who has recently taken up skiing.



The 55-year-old general children's surgeon, based in Northern Ireland, takes over from Dr Martin Bax who is standing down after 10 years.

Mr Boston joined the paediatric surgical service for Northern Ireland in 1977, and is hon senior lecturer in the department of surgery at Queen's University, Belfast.

He is one of the specialists who run the province's Spina Bifida Clinic.

He said Northern Ireland had "the doubtful distinction" of having the highest rate of spina bifida in the world, so clinicians there had built a wealth of experience.

Come dancing!

JULIA Hall and Trevor James hope to become regional dance champions for the ninth year on the trot this summer.

The pair, aged 34 and 31, have also been twice national champions against the best at ballroom from Scotland.

And with mum Angela, Julia is also a previous national PHAB couples regional champion (in which one partner is non-disabled).

Bristol-based Julia and Trevor are members of Concorde Wheelchair Dancers, who are hosting this year's competition. Teams from London, Devon, Cornwall and Southampton will be joining them on 16 June.

Concorde Wheelchair Dancers attracts people aged 20–70, some taking the pastime more seriously than others. There are also six non-disabled members who partner wheelchair-users for PHAB dancing.

The group meets weekly for team practice, couples practice and PHAB team practice. Some members also have private lessons.

Julia, the group's chairman, said: "On the whole, we all do very well at competitions and usually come home with a lot of trophies."

As well as practising for competitions, the group holds demo shows and runs collections to raise funds to enable dancers to travel to competitions.

● New members, male and female, of any age and disability, are always welcome. Phone Julia on 01275-833541, email angela.hall@ukgateway.net

Goodbye, Jon – but not for long!

A FUNDING glitch has resulted in us having to let Jon Burke go as co-ordinator of our *Your Voice* disabled members group – but, hopefully, just temporarily.

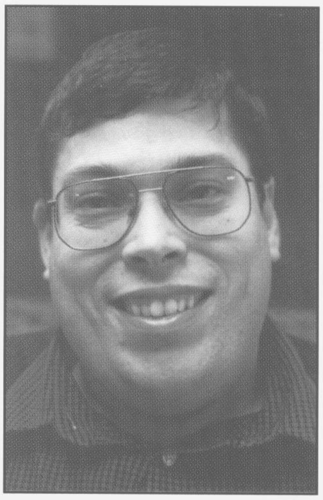
Jon's three-year contract came to an end at Christmas when his lottery funding ran out. But ASBAH kept him in post until the end of the financial year, hoping to have new funding in place so his job could continue.

Unfortunately, the money did not arrive, despite intense efforts to obtain it. So Jon *(right)* was put in the awkward position of having to say goodbye to colleagues, not knowing if he was going to return.

Your Voice goes on under the control of an active central steering group of volunteers, with some admin work being put in by staff at ASBAH national centre.

"For a while, you may hear less from the group than you have done recently. But it's not a case of the end being near, more that 'You ain't seen nothing yet!" said Jon. He also works part-time for Voluntary Action Leeds and is finishing a BA (hons) degree in politics and history at Huddersfield University.

John (34) organised one international and three national conferences as co-ordinator. There have also been five regional training and eight local group events.



Membership of *YV* has grown steadily under his influence – from 100 people three years ago to well over 250 nowadays. This year's programme will be announced shortly.

We haven't lost Jon to the *YV* group, which he helped set up 10 years ago when he became its first chairman. He's just been co-opted to the central steering group.

Linda Hams, ASBAH's assistant director (policy and marketing), commented: "We are very sorry not to have been able to keep Jon in post. However, we look forward to having him back when the new funding comes in – if he is still available."

TWO IMPORTANT PERSPECTIVES

Years of being left to 'get on with it'

A service-user's view by Patrick O'Flynn

WHEN I had a urinary diversion at 14, I received no help or support. No one told me how the operation would affect me afterwards.

Neither did I have parental support because I grew up in care and, after being shown once by a nurse how to change my bag, I was left to get on with it. I still remember being in the loo for two or three hours trying to work out what to do. I asked for help but staff had 150 other kids to look after. No one was going to change a bag for me two or three times a day.

Things haven't changed much 30 years on because my mate's just had the same surgery and he's only just realising what it means.

There wasn't a day when I didn't want to throw my bag away. I got fed up having to change it and hated it when leaks happened, often in shops or some public place.

I was conscious of this thing on my stomach and I hated having to explain it to people, particularly girlfriends.

I've had severe pain in my stomach because of the surgery, especially at night, but the worst side of it is the emotional side – learning to accept it and anticipating the reaction of others.

Some girls would say 'Errr' or run away when they found out I used a bag. Then I had the confidence to realise, if a girl was going to take that attitude, she was wrong for me. If I got an infection, I got smelly and the people around me would have to be understanding.

I was at a special school at a time when people with disabilities were locked away, not seen or heard, and were taken out on a special bus. But I knew I was like anybody else. I suppose it was my love of music that gave me confidence: I liked bands like Led Zeppelin and I related to other young fans of these bands.

It took me 18 years to get out of living in an institution and to get social workers out of my life. At 17, I went to live in a place for disabled adults. I got out as soon as I could find somewhere to live and trained to get myself a job.

I am 45 now, married for 11 years with two kids. That operation still affects my life even now. For instance, I had to explain to my kids why they can't sit on my stomach. And my bag still 'goes' at the most inappropriate time. It might need changing just as we're going out – even if it had been fine 10 minutes earlier. That puts a strain on a relationship.

A lot of people with life-long continence problems are frustrated that they have a procedure to go through several times a day to keep themselves dry. The nurses do the job for them in hospital and parents get on with it at home. Young people should be shown what to do and have it explained to them how important it is, right away, so they become responsible.

Parents have to be educated too. It all comes down to communication and this is exactly what was lacking when I was a teenager having major surgery and not told what was going on.

It also comes down to self-confidence. Perhaps young people feel nobody will want to know them

"I FEEL," said a mother, "as if I'm literally always in the shit."

I meet many families and individuals who feel that their lives revolve around bowels and bladders and some who hate every minute of it. We don't often talk publicly about the grittier bits of the subject and I'm writing this to try to open up some discussion and comment, not least from those people who have spina bifida. This is not an exercise in knocking the many committed medical professionals involved, more a recognition that emotions and not just mechanics affect continence management.

With more and more children with spina bifida being educated in mainstream schools, there are considerable pressures to have a good management system in place by the time the child is of school age; specialist professionals are very upbeat about the subject and parents are reassured by tales of under-fives merrily self- catheterising. That some do, I doubt not, but there are many and particularly those with hydrocephalus, who have both practical and motivational difficulties in this area. From nappies and pads, urinary diversions, indwelling catheterisation, micro-enemas, bunging up with Immodium and manual evacuation to artificial urinary

ON A VERY SENSITIVE SUBJECT FOR MANY READERS

It should be private but not nasty

An ASBAH Adviser's view
by ANGELA LANSLEY

sphincters, Mitrofanoff and ACE procedures – the methods have changed but still many young people growing up find it difficult to cope with these unaided and experience continence management as something that people do **to** you.

Many of the techniques are very stressful for carers and increasingly demand active participation and co-operation from the people with spina bifida. Most advisers will have heard graphic descriptions of trying to manage bowel washouts with wheelchair users who needed to be lifted onto the loo at exactly the right time before the floor was awash; of trying to catheterise and change children in the back of estate cars because there aren't suitable changing facilities in public loos; of having the family bathroom tied up for an hour or more for a bowel washout; of having to get up twice a night for over a year to catheterise a child after a bladder augmentation.

The child who had the bladder augmentation is still wet when she moves about but dry if she stays in her wheelchair. Her medical team consider her functionally continent and a success. She doesn't! What about the young woman who could stay dry if she were to self- catheterise but won't do so? She may well be a success statistically but perhaps not to live with.

Which brings me to perhaps the most difficult area and the effect of all these demands and interventions on children and young adults. Many **are** successfully managing their self-care, but there is a significant minority who are not. Some, like the 11-year-old who refuses to self-catheterise and tells his mother "You do it – it's your job", switch off from their bodies. They will have had their privacy invaded so many times; they will have been talked about (by people like me); their bodies seem to belong to other people. They may have lived in terror of the rustling nappies that give away their secret to other pupils in mainstream school; name-calling and abuse are common both in mainstream and special schooling. Some drive their families to distraction by refusing, despite constant prompting, to empty their leg-bags or urostomy bags until they leak or by continuing to sit in soiled pads. Some go into the loo to catheterise but don't actually do it or come home from a holiday with all their phosphate enemas unused. Stuffing used pads and soiled clothing away in drawers or under the bed is not uncommon even among adults.

Continence management can become the expression of rebellion and anger. Arguments over hygiene are common in families with adolescents but take on a different dimension with young people who have poor bowel or bladder control. Many seem not to notice or care that they smell, brothers and sisters often feel that they cannot bring their friends home to a smelly house and problems in personal hygiene can loom large in employment.

Just writing this makes me feel guilty – as if I'm sharing a nasty secret and letting down the people with whom I work, focussing on the impairment instead of on the social barriers and negative attitudes which exclude disabled people from society. But as poor personal hygiene is probably one of the biggest barriers to inclusion from nursery school to adult relationships and is clearly the cause of a great amount of family stress and anger, we have to look at how we can help disabled children and young people to feel good about themselves so that their high self-esteem is reflected in the care with which they look after their own bodies.

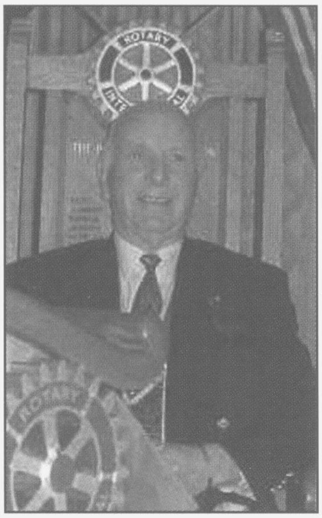
---

anyway, so why bother about keeping clean?

I've been through the attitude of nobody's going to want me ... but I eventually realised that I'm no different from any other bloke.

Each and every one of us is important whether we have continence problems or not. Each and every one of us has to keep ourselves clean for our own self-respect and the respect of others. Stoma bags are horrible things but something we have to accept. Then we can get on with the rest of our lives.

ASBAH's Fundraising Manager is Donna Treanor
Tel: 01733-555988 donnat@asbah.org



Luton Rotary put ASBAH in the frame

ONE OF the oldest Rotary Clubs in the east of England has taken ASBAH under its wing. The 58 members of the Rotary Club of Luton, founded in 1927, have adopted us as one of the charities they support this year.

Their sponsorship will include a study day on 1 November for 100 participants at the Chiltern Hotel, just off the Dunstable Road, Luton – venue for the club's regular Thursday lunches – and other fundraising.

Club president Trevor Holland, who has spina bifida, endured 17 operations before he was six years old. He didn't walk until he was 11, and only then with the aid of calipers and extensive strapping.

"I don't know how I did it but, by the time I was 19, I had got rid of all those contraptions and I have been able to keep mobile since then", said Mr Holland *(pictured)*. "It was a time when there were no support groups and certainly no ASBAH, which I only found out about three years ago."

"I have been able to lead a comparatively normal life. While this year the club will continue its support of other groups in the community, I'm delighted that members took up my suggestion that during my presidential year we should also support ASBAH".

24–hour dance raises £350

PORTSMOUTH pub regulars danced the night and day away and raised £350 for ASBAH.

Taking part in the 24-hour dance marathon was ASBAH shops driver Keith Collins, who nominated ASBAH as one of the charities to benefit from the aching feet.

Wendy Mitchell, landlady of the Robert Peel Pub and former president of the Licensed Victuallers' Association, handed over the cheque to our national shops co-ordinator Christine Cousins and Keith at a special presentation evening.

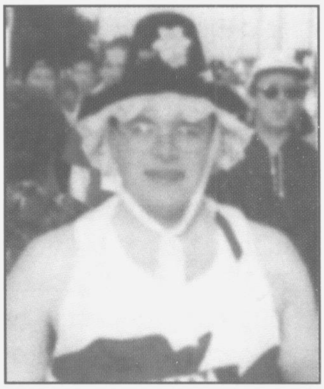
Our grateful thanks to everyone at the pub for making the dance marathon such a success.

- *Picture shows Wendy Mitchell (left), Christine Cousins and an exhausted Keith Collins.*

Thanks Teifion!

WEARING a Welsh ladies' hat, patriotic Welshman Teifion Woodward ran the Great North Half Marathon, raising £200 for ASBAH.

The 29-year-old student nurse, who is not afraid to look a bit ridiculous for charity, is exiled in London at the Royal Free Hospital in Hampstead in his final year of training.

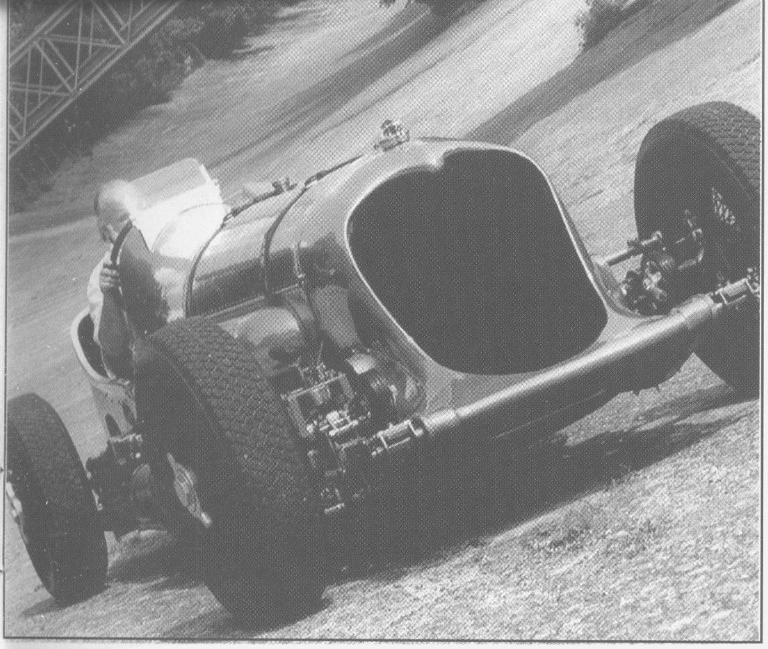


His girlfriend has hydrocephalus and mild spina bifida and he has worked on a neurological ward.

Teifion, from Abertillery, said: " I have gained some knowledge and insight into spina bifida and hydrocephalus, and know what splendid work you do in supporting people with these conditions."

Teifion took part in the 1998 Flora London Marathon.

Enjoy a Dream Ride at Brooklands 28 July



● *John Cobb's 24-litre Napier-Railton which broke the Brooklands outer circuit lap record of 143.44mph in 1935. It may be fired up on 28 July.*

THE HEYDAY of vintage and classic car motoring will be relived at the famous Brooklands circuit, near Weybridge in Surrey, on Saturday 28 July – when parents can bid for a chance for children with spina bifida and/or hydrocephalus to enjoy a dream ride.

The first 25 phone or email bids from parents will qualify their children for a free two-mile ride in a supercar that day.

The 'Dream Ride' route includes the old runway from where Selwyn Edge made the first English aircraft flight and the historic banked oval – home of British motoring racing before the Second World War.

The event is being staged by the Sporting Bears Motor Club, a classic car outfit which has chosen ASBAH as one of three charities it is supporting this year.

"We've got some really good cars lined up, old and new, some vintage (Bentleys etc) plus Jags, Maseratis, Ferraris and Porsche", said club organiser Roger England, from Shefford, Bedfordshire.

There will also be hot air balloon rides, go-karts and pillion rides with the Honda Goldwing Club, as well as the chance to sit in a Formula One racer. Brooklands will lay on barbecues, ice-cream vans and other refreshments to make it a real family day out.

Phone ASBAH publicity on 01733-421316, email tonyb@asbah.org, to bid for a Dream Ride for your child, or simply to find out more about the event. We hope to carry photos from the event in the September *Link*.

You got to be fit to fight for ASBAH in Army's challenge!

A TEAM of soldiers travelled to Germany to compete in an army half marathon and their success raised £820 for ASBAH.

The mission was organised by Lance Corporal Patrick McGeever in memory of his nephew, John Patrick, who died 15 years ago.

Patrick (35) was joined by five other colleagues from 5 General Support Medical Regiment, based in Preston, Lancashire.

And Bill Guest, a regular at the Barley Mow pub in Wardend, Birmingham, where Patrick's mother lives, helped to kick-off the funds by agreeing to have his hair and flowing mane of a beard severely cut.

Over the years, Patrick – the unit's physical training instructor as well as a vehicle mechanic – has raised thousands of pounds for charity.

ASBAH would like to thank Patrick, his colleagues and regulars at the Barley Mow pub for their part in raising such a magnificent amount for us.

● *Photo on the right shows (from the left) Wade Pasiful, Rob Barr, Steve Allen, Jas Thacker, Pat McGeever and Steve Mackinnon preparing for the Army half-marathon in Germany.*

dates for your diary

Our ChairAbility Challenge

INTEREST is rising in our second annual ChairAbility Challenge, ASBAH's national awareness day being held on Saturday 13 October.

The event pits MPs and celebrities against people with spina bifida and/or hydrocephalus in games of wheelchair basketball. It is being held in sports centres round the country.

As this page was going to press in March, requests for ChairAbility info packs had come in from Stan Fitzgerald (Southampton ASBAH), *Your Voice* member Kevin Towner (Sussex), and Jaz Dhani (Disability Action in the Borough of Barnet).

The packs contain checklists and model invitations to help organisers run their own challenges. Copies are avalable free from ASBAH publicity on 01733-421316, email tonyb@asbah.org

The day showcases the abilities of disabled people. Please take part in the day.

MP shadowing

A DOUBT has been cast against RADAR's ability to run its annual MP shadowing event in December. The organiser has left for another post; no one has yet been named to replace her.

Your Voice member Zem Rodaway and Maxine Kruk (North Yorkshire) have been added to the list of six other ASBAH members wishing to take part this year, in case the event does go ahead.

RADAR is being re-organised following its merger with another charity.

Upcoming events

Annual meeting

Saturday 12 May, Corby
Northamptonshire ASBAH's AGM, Danesholme Club, Motala Close, Corby, 3.15pm. Transport available. *Alison Walter, 01604-634419.*

Bedford coffee

Saturday 12 May, Bedford
Coffee morning, 10.30-noon, Addison Centre, Addison Howard Park, Bedford Road, Kempston, Bedford. *John Richards, ASBAH area adviser, tel: 01908-610611.*

Dunstable meeting

Monday 14 May, Dunstable
Monthly meeting for parents/carers of children/young people with spina bifida and/or hydrocephalus, organised by the South Bedfordshire Support Group. 1–3pm, Disability Resource Centre, Poynters Road, Dunstable. *Valerie Bottoms, tel: 01582-757745.*

Support for BIH

Saturday 2 June, Banstead
Support day for people with BIH & informal get together. 11am–2pm, Civic Centre, The Horseshoe, Banstead, Surrey. *ASBAH South East Centre, tel: 0208-449 0475 jof@asbah.org*

Leeds drop-in

Wednesday 6 June, Leeds
Northern Region monthly drop-in, ASBAH House North, 64 Bagley Lane, Farsley, Leeds. 10–noon. *Bernadette Baldwin or Rachael O'Brien, tel: 0113-255 6767.*

Bromley coffee

Monday 11 June, Bromley
Coffee morning organised by South Thames ASBAH, 10am–noon, United Reform Church, Bromley. *Peter Winterton, tel: 0208-462 3011.*

Mobility Roadshow

15–17 June, Crowthorne
ASBAH is at Europe's premier outdoor mobility event, Transport Research Laboratory, Crowthorne, Berks, 10am–6pm Fri & Sat; 10am-4pm Sunday. Free admission. Test drive a wide range of adapted vehicles (bring driving licence), over 200 exhibitors. *Details and a test drive registration form, from Mobility Choice, 01344-770946.*

Research Society

27–30 June, Sweden
45th annual scientific meeting of The Society for Research into Hydrocephalus and Spina Bifida (SRHSB), University of Uppsala, Sweden.

Dream Rides

Saturday, 28 July, Brooklands
Rides for ASBAH members at the historic Brooklands motor racing circuit, Weybridge, Surrey. Organised by the Sporting Bears classic car club. *For your invitation and to book your ride, contact ASBAH publicity on 01733-421316, email: tonyb@asbah.org*

DAVE'S DIARY

david.fulford-brown@ntlworld.com

THREE years ago I got a car from Motability. Now the time has come to replace it with another. It's just a stupid pile of nuts, bolts and wheels. It swallows loads of fuel and loads of money. It spews out health-destroying pollution. And still it feels like I'm parting with an old friend!

One of the things that makes me regret having to hand 'my' car back is that I've had so little trouble with it. With the Motability scheme whenever there was any kind of problem, I just sent it back to the garage, or called to the breakdown people for help. The breakdown people were fabulous. They sorted everything out when I got a puncture, despite the geniuses at the garage locking the wheel nuts but forgetting to give me the key (which you need to do if you want to get the wheel off without a chainsaw). The breakdown guy got to me and stayed with me until he'd sorted everything out. All in all, having a car from Motability has been great.

But before you think I'm turning mushy and sentimental, there is one other reason I'm sorry I have to get a new car: it's because as well as all my benefit, I'll have to hand over a large chunk of my hard-earned and all too limited cash, which I'm not going to get back. Worse, in three years time if I want another car I'll have to hand over another large chunk of cash.

Experienced users of the Motability scheme will, no doubt, be writing in now, complaining that I don't *have* to get the kind of car which you pay a huge bundle for. I could go for one of the 'nil deposit' cars on the list. Well, I could. But there are precious few of them about these days. And I don't want to offend anyone here, but the 'zip to pay up front' cars seem to be rather lacking in zip anywhere else.

Three years ago I got a car which didn't need any money up front but didn't list the steering wheel as a feature of the car! Today my little hatchback requires about 12 hundred quid up front. Start lusting after something like a Saab 9000 or an Audi and you are looking to pass over several thousand pounds – if you have them! If the cars are going to cost so much up front, why put them in the scheme? Who can afford them? Or is everyone reading this earning far more than me?

The price increase is apparently because Motability prices are calculated on second hand car prices. As they drop, so the money to pay up front increases. So while everyone else gets a cheaper deal from dropping car prices, us poor Motability bods gets hammered. Something's very wrong there, I think! Surely Motability can use its clout, as a major buyer of new cars, to push the prices down? And as for the cost of adaptations? Hundreds of pounds for a bunch of rods and bolts? Don't even get me started!

Despite all my whinging about prices, the garage knows I'll pay up. Because, without a proper public transport system, a car means mobility and freedom!

E-MAIL CONTACTS

Here is our regular list of e-mail contacts in the UK and around the world. If you would like to go on the list, contact lizc@asbah.org

Valerie Bottoms, mum (Bedfordshire)
valerie.bottoms@ntlworld.com

Graham Hudson, age 28 (Rothwell)
ghudson@oldbothwell.freeserve.co.uk

Paul Manning, Mid Wales ASBAH
Maesafallen60@cs.com

Stephanie Meikle, age 23 (Renfrew)
steffy_m@yahoo.com

Sharon Murray, mum to three-year-old Sean
Sharon.Murray@btinternet.com

Rachel Roberts, age 25 (Wrexham, N Wales)
phabulass@aol.com

Debbie Sanderson, age 29 (H)
debbie@sanderson85.freeserve.co.uk

Rachael Seymour, age 8 (Co Durham)
rachael@steveseymour.demon.co.uk

Balbir Singh, age 41, (London)
bsingh2@cwctv.net

Bryan Stevens, age 15 (Grantown-on-Spey)
bryanstevens@lineone.net

LeeAnn Tacchi, age 20 (USA)
leeann13_@hotmail.com

Shirley White, age 55 (USA)
shirleyw@hp9000.macc.cc.mo.us

holiday lets

When booking, check to make sure the accommodation suits your particular needs.

NAISH HOLIDAY VILLAGE

Cliff-top park with "excellent" status. New Milton, Hampshire. Excellent site facilities within 100 yds with indoor/outdoor pools; restaurant, bar, take-away. Fully equipped, 2 bedroom, fully wheelchair accessible log cabin accommodation. Sleeps 6, well furnished. Free club membership.

GRANGE COURT HOLIDAY VILLAGE – Park with "good" status. Goodrington Sands, Devon. Excellent site facilities within short walk, with indoor/outdoor pools, restaurant, bar, take-away. Fully equipped, 2 bedroom, fully wheelchair accessible mobile home. Sleeps 4-6, well apppointed. Free club membership. (Purchased with funds from the National Lottery).

MILENDREATH HOLIDAY VILLAGE – Excellent seaside site with good facilities, just outside Looe in Cornwall. Restaurant, clubhouse, indoor pool. Fully equipped and wheelchair accessible 2 bedroom chalet accommodation. Sleeps 6 – well-furnished and comfortable. Free club membership.

Details: Mr P Cash, tel: 01425-672055, email: petercash1@talk21.com Bournemouth Spina Bifida Association, registered charity no. 261914.

FOR SALE

TOIRIER manual wheelchair, blue, vgc, 10 years old, solid tyres, 16" seat. Will give it away if donation made to ASBAH. *Mrs Chapman, tel: 01763-245070 (Royston, Herts).*

MAYFAIR Freerider 4-wheel scooter, 4 months old, cost £2,565, accept £1,200 ono. *Mr Spence, tel: 01623-469897 (Mansfield, Notts).*

SELSEY, WEST SUSSEX (SASBAH)

Fully equipped, purpose-designed for wheelchair access, mobile home. Sleeps 6, ramp and large veranda, payphone, colour TV, midi stereo etc. Clubhouse entertainment, heated swimming pool, free site bus service. Nature reserves and places of interest nearby. *Details from Julie Parks, tel: 01273-472298.*

ISLE OF WIGHT ASBAH

Recently refurbished, fully equipped, 2 bedroom bungalow. Sleeps 6. Wheelchair accessible. Clubhouse, shop, local indoor heated pool. Beautiful area. Own transport advisable. Excellent rates. *Details: Mrs Griffiths, 3 Western Road, Shanklin, Isle of Wight PO37 7NF, tel: 01983 863658, www.iowasbah.i12.com*

BERWICK COTTAGE, EAST HARLING, SOUTH NORFOLK (CATEGORY 1)

Modern, purpose-built, self-catering cottage. Ground floor accommodation for up to 2 people (single beds) with disabilities. Scan 700 beds; Clos-o-Mat; overhead track hoist bedroom-to-bathroom, wheelchair shower and much more. Up to 4 carers/family/friends upstairs. Awarded Grade 1, Holiday Care. Open all year. Low rates Winter/Spring (£250 to £350 per week) – full central heating. Helpful caretakers demonstrate equipment, but otherwise total privacy in pretty village with accessible pub, GP, shops. *Cottage brochure, Lin Berwick, (tel: 01787-882111). Booking forms and full information, George Tickner, The Lin Berwick Trust, (registered charity), 0208-595 7056.*

ORLANDO, FLORIDA – House with a heart for disabled travellers! Spacious, luxury, adapted bungalow situated on golf course. Three double bedrooms, two bathrooms (Mangar bathlift installed), cable TV, free local telephone calls, free Country Club membership. 24-hour 'on-call' management company. 15 minutes Orlando Airport. 20 mins Disney. Paraplegic owner. *Sue Fisher, 5 Park Lane, Broughton Park, Salford M7 4HT, tel/fax: 0161-792 3029.*

LETTERS.... LETTERS.... LETTERS... LETTERS.... LETTERS..

Tired joke came out in the wash!

I TOOK my 12-year-old daughter Kylie to have her hair cut and washed. When finished, the hairdresser said she had felt some lumps in Kylie's head and I explained that Kylie had a condition called hydrocephalus with two valves inserted. The hairdresser told me that she had come across this before and knew how you had to pull out the plugs to drain the water out from time to time! Simple, eh?

Mrs Gill Pratten, 12 Green Hill, Cleethorpes, NE Lincs DN35 9PT

He's got a pacemaker and a shunt

MY son Andrew, 11, has a shunt and pacemaker and I think, at times, the pacemaker may interfere with the shunt. I would like to hear from another family or individual who has experience of having both of these devices so that we can compare notes.

Mrs Joan Flanagan, 63 Cloughend Road, Hattersley, Hyde, Cheshire SK14 3PW.

DIRECTORY OF INDEPENDENT LOCAL ASSOCIATIONS

AFFILIATED ASSOCIATIONS

BARNSLEY
Mr Geoff Jenkinson
12 St Leonard's Way
Ardsley, Barnsley
S Yorks S71 5BS
Tel: 01226-292546

BEDFORD
Mr R C Simmonds
16 Parkstone Close
Bedford MK41 8BD
Tel: 01234-400068

BOURNEMOUTH, CHRISTCHURCH & DISTRICT
Mrs Gill Lanning
43 Rothesay Drive, Highcliffe
Christchurch, Dorset, BH23 4LD
Tel: 01425-276820

BRISTOL & DISTRICT
Mr G Egan
64 Rookery Road
Knowle, Bristol BS4 2DT
Tel: 0117-9777942

BUCKS & EAST BERKS
Mrs Abigail Biscoe
15 Elm Road
High Wycombe
Bucks HP12 4TA
el: 01494-639773

BURY & BOLTON
Mr David Clyne
51 Cuckoo Lane, Whitefield
Manchester M45 6WD
Tel: 0161-798 7804 (after 4pm)

CAMBRIDGE & DISTRICT
Mr Tony Proud
10 Newlands Road
Whittlesey
Peterborough
PE7 1YX

CHESTER & DISTRICT
Mrs P Ithell
34 King Edward Street
Shotton, Deeside
Clwyd CH5 1DW
Tel: 01244-811074

COVENTRY
Mrs N Newman
11 The Earls Court
Cheylesmere
Coventry CV3 5ES

DERBYSHIRE
rs A Hewitt
t Merryn, 20 Burley Hill
Allestree, Derby DE3 2ET
Tel: 01332-841893

DUDLEY & WOLVERHAMPTON
Mrs Lorna J Wootton
14 Leveson Road
Wednesfield, Wolverhampton
West Midlands WV11 2HF
Tel: 01902 738724

GRANTHAM
Mrs J Asken
88 Goodliffe Road
Grantham, Lincs NG31 7QB
Tel: 01476-401643

GREENWICH & DISTRICT
Mrs M Mears
29 Wellmeadow Road
London SE13 65Y
Tel: 0208-244 3526

HAMPSHIRE NORTH, W SURREY & S BERKS
Miss Samantha Phillips
41 Lynchford Road
Farnborough
Hants GU14 6AN

HERTS AND SOUTH BEDS
Mrs Jennifer Hammond
28 Gladeside
St Albans
Herts AL4 9JA
hamrock@supanet.com

HUDDERSFIELD
Mr Stephen Bolton
361 Bradley Road
Huddersfield
HD2 1PR
Tel: 01484-424479

KENT
Mrs S Stevens
7 The Hive
Northfleet
Kent
DA11 9DE
Tel: 01474-536202

LEEDS & BRADFORD
c/o ASBAH North
64 Bagley Lane
Farsley
Leeds LS28 5LY
Tel: 0113-255 6767

LEICESTERSHIRE
Mrs A Twomlow
29 The Crescent
Market Harborough
Leicestershire
LE16 7JJ
Tel: 01858-432967

LINCOLN & MID LINCS
Mrs P Malson
"Pinfold"
Chapel Lane
North Scarle
Lincoln
LN6 9EX
Tel: 01522 778781

LINCOLNSHIRE SOUTH
Mrs P Mason
67 Boston Road
Heckington
Sleaford
Lincs
Tel: 01529-460322 (after 6pm)

LONDON NORTH WEST
Mrs H Prentice
37 Milton Road
Hanwell
London W7 1LQ
Tel: 0208-579 4685

LONDON SOUTH
Mrs S Cudd
15 Woodvale Walk
Elder Road
W Norwood
London SE27
Tel: 0208-761 2400

NORTHAMPTONSHIRE
Mrs Alison Walter
12 Adam Avenue
Northampton
NN1 4LQ
Tel: 01604-634419

OXFORDSHIRE
Mrs Shirley Dale
14 South Row
Chilton
Didcot
Oxon OX11 0RT
Tel: 01235 -834785

PRESTON
Mrs S Thompson
34 Beatty Road
Southport
Merseyside PR8 6LB
Tel: 01704-542589

St HELENS & DISTRICT
Joanne Barrett
10 Halefield Street
St Helen's WA10 2DE
Tel: 01744-612860

SHEFFIELD
Mrs Barbara Clark
35 Woodhouse Lane
Beighton, Sheffield S20 1AA
Tel: 0114-269 9299

SOMERSET
Mrs Iris Coton
3 Court Gardens, Yeovil
Somerset BA21 3LZ

SOUTH THAMES
Mr Peter Winterton
27 Cranbrook Close
Bromley, Kent BR2 7QA
Tel: 0208-462 3011

SOUTHAMPTON & DISTRICT
Mr S J Fitzgerald
32 Ellis Road, Thornhill
Southampton SO19 6GR
Tel: 023 8040 2644

STAFFORDSHIRE
Mr Reay Pearman
2 Spode Grove
Westbury Park, Clayton
Newcastle-under-Lyme ST5 4HF

STAINES, HOUNSLOW & DISTRICT
Mrs Pamela Page
237 Upper Halliford Road
Shepperton
Middx TW17 8SP
Tel: 01932 783991

STOCKPORT & TAMESIDE
Mrs Tracy Ryan
265 Adswood Road, Adswood
Stockport SK3 8PA
Tel: 0161-474 1299

SUNDERLAND
Mr J Pounder
42 Gowanburn
Fatfield, Washington
Tyne & Wear NE38 8SG
Tel: 0191-415 1725

SURREY
Alan Twyford
86 Tolworth Park Road
Tolworth, Surbiton
Surrey KT6 7RH
Tel: 0208-390 0853

SUSSEX
To be appointed

TRAFFORD & SALFORD
Mrs T Gaynor
Davis Court, Cyprus Street,
Stretford, Manchester M32 8AX
Tel: 0161-865 0222 (am only)

WARRINGTON & DISTRICT
Miss Nancy Gleave
16 Hilltop Road, Woolston
Warrington
Cheshire WA1 4PD
Tel: 01925-819329

WESSEX
Mr T Poole
123 Gerrards Green
Beaminster,
Dorset DT8 3EA
Tel: 01308-862614

WIGAN, LEIGH & DISTRICT
Mrs Pat Stridgeon
24 Greendale Crescent
Leigh WN7 2LQ
Tel: 01942-676091

WIRRAL
Mrs M Appleyard
28 Stavordale Road
Moreton
Wirral, Cheshire CH46 9PR
Tel: 01516-784409

WORCESTERSHIRE
Mrs Ann Cotter
49 Brueton Avenue
Fringe Green
Bromsgrove
Worcs B60 2AW

YORKSHIRE NORTH
Miss Faith Seward MBE BA
45 The Paddock
York YO2 6AW
Tel: 01904-798653

WALES

Llanelli
Mrs Anthea James
61 Westland Close
Loughor, Swansea SA4 2JT
Tel: 01792-428004

Mid Wales
Paul Manning
60 Maes Afallen
Aberystwyth SY24 5BL
Tel: 01970 820581

North Wales
Mrs V Conway
4 Ewloe Drive
Bodnany Road
Llandudno
Tel: 01492-878225

South Wales
Mrs Brenda Sharp
4 Lakeside, Barry
S Glamorgan CF62 6SS
Tel: 01446-735714

NORTHERN IRELAND
Mr J Rippey
Long Eaves
24 Tullywiggan Road
Cookstown
Co Tyrone BT80 8SD
Tel: 028-8676 2290

NON AFFILIATED ASSOCIATIONS

Blackpool & Fylde
Mrs Diane O'Hagan
83 Boothley Road
Blackpool
Lancs FY1 3RR

Calderdale
Mr A L Crowther
12 Elm View
Huddersfield Road
Halifax HX3 OAE
Tel: 01422-341497

Cannock & Walsall
Mr Ken Hall
17 Wallhouse Street
Cannock, Staffs
Tel: 01543 -504847

Chesterfield
Mrs K Tomlinson
23 Hathern Close,
Brimington Common
Chesterfield, Derbys
Tel: 01246-272724

Cornwall
Helen Youngman
13 St Petry, Gears Lane
Goldsithney
Penzance
Cornwall TR20 9LA
Tel: 01736-710261

Devon
Charles Harper
23 Sturcombe Avenue
Paignton
Devon TQ4 7EB
Tel: 01803-522256

East Anglia
Mrs L Turner
7 Stow Gardens
Wisbech
Cambs PE13 2HS
Tel: 01945-466205

Essex
Mrs R McCarthy
26 Brixham Gardens
Ilford, Essex IG3 9AX
Tel: 0208-594 1852

Isle of Wight
Mr D J S Sprake
Springfield, Town Lane
Chale Green,
Ventnor
I W PO38 2JS
Tel: 01983-551234

Lancaster, Morecambe & District
Mrs M Dyson
25 Royds Avenue, Heysham,
Morecambe LA3 1PA

Nottinghamshire
Mr Allan Barratt
127 Limetree Road
Hucknall, Notts NG15 6AW
Tel: 0115-953 7291
Fax: 0115-953 2081 (8am - 6pm)

Rochdale
Mrs Anne Lawton
20 Spencer Street, Chadderton
Oldham, Lancs
Tel: 0161-6524487

Whitchurch (Salop)
Mrs E Calder
Southfork, Sedgeford,
Whitchurch, Salop SY13 1EX
Tel: 01948-663627

OTHER ASSOCIATIONS

SCOTTISH SBA
Executive Officer:
Mr Andrew Wynd
190 Queensferry Road
Edinburgh EH4 2BW
Tel: 0131-332 0743

IRISH ASBAH
Ms Claire Gill
Hon Secretary, Irish ASBAH
Old Nangor Road
Clondalkin, Dublin 22
Tel: 00 3531 4572326

JERSEY, Channel Islands
Mrs Ursula Emmanuel
Priory Gardens
La Grande Route de St Clement
St Clement
Jersey, JE2 6QQ
Tel: 01534 -853019

Association secretaries requiring changes to this list should contact: **LINK EDITOR, ASBAH, 42 PARK ROAD, PETERBOROUGH PE1 2UQ Tel: 01733-555988 Fax: 01733-555985.**

SpeediCath : Catheters

The **First** Ready to use **Coated** Intermittent **Catheter**

"No need to fill"

Prepacked in water

"No need to worry"

Simple to use

"No one need know"

Privacy wherever you are

"No need to wait"

Ready to use

For further information/samples either complete and return the coupon below or telephone:
FREEPHONE UK: *0800 220 622* **FREEPHONE EIRE:** *1800 409 502* **www.coloplast.co.uk**

Coloplast

Please send to: **Coloplast Ltd, Freepost, ANG 3546, Peterborough, Cambs. PE2 6BR**

Forename	Surname	
Address		
	Post Code	Tel
Which catheter are you currently using		Catheter Size